

# PERSPECTIVE

SUMMER 2010 | VOLUME 121

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# CEO's Message

Kari Luther Carlson

President & CEO

Summer is definitely in the air, and that means things are incredibly busy at the national offices of the Tuberous Sclerosis Alliance. It also means the current Fiscal Year will soon end on June 30, 2010. Therefore, I want to start by thanking outgoing Board Chair Celia Mastbaum for her incredible leadership, stewardship and compassionate dedication to the organization. Celia served as Vice Chair last year, Chair this year and will also continue to support the TS Alliance as Immediate Past Chair in the coming months, leaving an impressive imprint on how we operate.

I also want to salute the dedication of several board members whose terms are coming to an end: Terry Elling, Tommy Lindsey, Rob Thurston and Chris Sheffield. As most of you probably know, serving on the Board of Directors can almost be a full-time job, and all these individuals have helped the organization move forward in their own special ways. Thanks so much for all you've done on behalf of our constituents, their families and in our search for better treatments and a cure.

Spring and summer also mark the beginning of the TS Alliance's Step Forward to Cure TSC walkathon season! This year will feature more than 30 walks taking place across the country, most in May/June, but a few in April and a few this coming fall. The TS Alliance certainly values the significant funds raised by these events, but the board and staff have also come to realize the important role the walks play in bringing together individuals and families for companionship, support and as a true "community" that is working toward a common goal. We often hear how for some people, the walks are the only time of the year they are able to be with others affected by TSC, and we are very proud Step Forward to Cure TSC has grown so much over the years. Thanks to all of you who spearhead and run the walks, to our national sponsors Lids and Lundbeck, and to each and every one of you who attend. No matter how much you raise, just being there makes a true difference to others.

Please know the TS Alliance is well aware that the current economy continues to pose challenges not only to our ability to raise funds, but also to all of you in your daily lives. As a result, the board and staff have been discussing the timing of the next National TSC Conference. You can probably imagine this effort requires significant additional fundraising to help supplement the cost to attendees as well as a huge staffing commitment. Because of these financial challenges to the organization – and the cost to our constituents who would attend, we will re-evaluate the National TSC Conference in December 2011. We will certainly keep everyone updated.

While we realize conferences offer the optimal educational opportunities, the TS Alliance is providing cost-effective

ways to share important breakthroughs in research and clinical care and give you support when needed, including:

- **Research Teleconference Series** – these are free of charge and offered periodically throughout the year. For those unable to attend, we post the audio files on our website so you can listen at your convenience.
- **Town Hall Meeting Educational Series** – these new local Community Alliance events bring together those affected by TSC with major researchers, TSC Clinics and clinicians. Look for more information on these elsewhere in this issue.
- **Perspective** – this magazine continues to be one of our best vehicles to keep everyone updated, particularly on current research efforts and breakthroughs.
- **Website** – [www.tsalliance.org](http://www.tsalliance.org) continues to offer the most current information available and I encourage you to visit it often as we are constantly updating the site and adding new features.
- **Director of Advocacy & Education** – Dena Hook is available to help support you in a number of ways. Many of you know her because of her expertise in educational advocacy, but she also offers much more including being able to help you find medical care, put you in touch with others in your area for support, host monthly online sibchats as well as adult teleconferences and is available to just listen to you when needed.

Finally, I want to thank all of you who took the time to complete our recent Online Constituent Survey as it will provide a good blueprint for the organization's efforts to address the needs of our TSC community in the future. We value all of your thoughts, suggestions and even the complaints! Your feedback is important.

I hope you enjoy a wonderful summer and please remember to continue to spread awareness of TSC. Join me in making a pledge to tell one additional person per week about tuberous sclerosis complex, whether it's a chance meeting with a new person, sharing with an old friend through Facebook or contacting your local newspaper. Let's continue to fight – together – for a cure.





# Special Events



Patricia Heaton



Buzz Aldrin

On April 11 the **9th Annual Comedy for a Cure** took place at Boulevard3 in Hollywood, CA. The evening kicked off with Hosts Patricia Heaton and Leeza Gibbons along with a presentation from our very own Dr. Vicky Whittemore who gave a brief update on current TSC research and the hope that lies ahead. As always there was the fabulous live auction hosted by our long-time supporter and auctioneer Damon Casatigo and outstanding comedic performances by Ray



Larry Miller



Leeza Gibbons



Ray Romano

Romano, Larry Miller, Mike Polk, and Jeff Allen. This year's Honorees were Craig and Cindy Cunningham of C&C Market Research. Together everyone helped in raising \$250,000 for the TS Alliance! A very special thank you to our event Co-Chairs Dr. Rick and Jennifer Glassman, Auction Chair Julia Cohen, and the planning committee.

On January 24 the **17th Annual Joey Holuboev TSC/Pampered Chef Charity Auction** took place at the Cudahy Family Library in Cudahy, WI. This year's auction raised its most ever, \$3,500! Thank you to Lundbeck for sponsoring this year's auction and a very special thank you to Pam Sztukowski for



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### Kari Luther Carlson

President and Chief Executive Officer

### Jaye D. Isham

Managing Editor,  
Senior Director of Communications

If you have opinions, questions or articles for *Perspective*, we would like to hear from you. Please contact the managing editor to obtain a submissions form and guidelines.

*Perspective* is intended to provide basic information about tuberous sclerosis complex. It is not intended to, nor does it, constitute medical or other advice. The Tuberous Sclerosis Alliance (TS Alliance) does not promote or recommend any treatment, therapy, institution or health care plan. Readers are warned not to take any action without first consulting a physician. Commentary expressed herein reflects the personal opinions of the author and does not necessarily reflect the official views of the TS Alliance. Information contained in the TS Alliance database is confidential and not provided nor sold to third parties.

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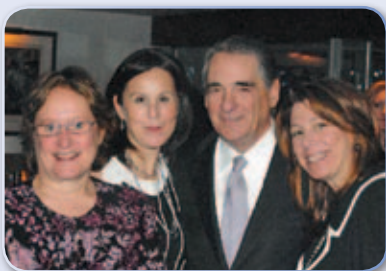
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her tireless and many, many years of support in raising funds and awareness of TSC in memory of her son Joey.



On February 24 the **9th Annual DC Food & Wine Tasting Event** took place at Morton's, the Steakhouse raising more than \$105,000. The evening began with event Co-Chairs Julie Blum and John Poutasse who thanked Morton's and our presenting sponsor, the Winifred M. Gordon Foundation. A special video was shown featuring one of our local Metro DC TSC families – Rob and Lisa Moss, whose son Evan has TSC. Dr. Vicky Whittemore, the TS Alliance's Chief Scientific Officer, gave the crowd an update on the exciting state of TSC research across the nation and the President & CEO Kari Luther Carlson then helped honor PhRMA CEO Billy Tauzin for his national leadership in advocating for access to medicines to treat all illnesses, particularly lesser known diseases like TSC. Thank you to everyone for making this event such a positive experience.



Dr. Vicky Whittemore, Kari Luther Carlson, Billy Tauzin and Board Chair Celia Mastbaum at DC Food & Wine Tasting.

## TS Alliance Announces 2009 Volunteers and Community Alliance of the Year



Kari Luther Carlson (far left) and Jenny Smiley (far right) with Volunteers of the Year Missy Anderson, Roxanne Rios, Susan Campbell and Ron Heffron.

Each year, the TS Alliance honors four individuals for their outstanding commitment and dedication to the organization and one Community Alliance for its outstanding commitment to community service, increasing awareness of TSC in their local area and their dedication to furthering the mission of the TS Alliance. Recipients are recognized during the week of the March on Capitol Hill at the Board of Directors and Annual Leadership Meeting.



Kari and Jenny with TS Alliance of the Rocky Mountain Region Chair Dana Holinka.

## NEW: 2010 TS Alliance Town Hall Meetings

### Join Us for Educational Opportunities Across the Country

Plan now to attend a town hall meeting to make stronger connections with peers, researchers, and clinicians in your community. Don't miss this opportunity to meet these dedicated

clinicians and researchers who care for hundreds of individuals with TSC and other families living with TSC.

### Who Should Attend?

- Parents and caregivers.
- Adults with TSC.
- Professionals who support people who have TSC.
- Anyone who wants to learn more in a relaxed, open and casual town hall setting.

### What Will Be Covered?

- Update on current research in TSC.
- Explanation of the clinical trial process.
- How to make informed decisions about participating in future clinical trials.
- How basic research translates into clinical care.
- Upcoming community activities.
- Question and answer period.
- Feedback encouraged!

### Dates and Locations

- July 24: Nashville, Tennessee
- July 31: Cleveland, Ohio
- August 1: Houston, Texas
- August 14: Fairfax, Virginia
- August 21: Mountain Brook, Alabama
- October 23: Boston, Massachusetts
- September 24: Cincinnati, Ohio
- September 25: Pittsburgh, PA
- TBD: California
- TBD: Georgia (Atlanta)
- TBD: Illinois
- TBD: Minnesota
- TBD: New York
- TBD: Pennsylvania (Philadelphia)

For more information please contact Dee Triemer at (800) 225-6872 or [dtriemer@tsalliance.org](mailto:dtriemer@tsalliance.org).

*The TS Alliance Town Halls are supported by an educational grant from Novartis. Per our corporate relations policy, the TS Alliance maintains complete control of the content and materials related to these Town Hall meetings. The TS Alliance selects the speakers and per our privacy policy no outside organization has, or will ever have, access to mailing lists or private information.*

## From the Board Chair . . .

As the TS Alliance's current Fiscal Year comes to an end, I am writing my last letter to you as Chair of the Board of Directors. While the economy has been challenging for many of us over the last few years, I'm quite pleased that the TS Alliance has not only weathered the financial storm admirably, but has also had impressive successes, particularly in advancing our research initiatives. I am ending my term very satisfied with how the organization is positioned for the future.

I'm very pleased to announce that David Parkes will be Board Chair in the new fiscal year, supported by Vice Chair Henry Shapiro, Secretary Matt Bolger and Treasurer Rita DiDomenico. All of these current and prospective officers of the Board bring strategic strengths and skill sets which will help the organization advance its mission and achieve its goals. I know you will all join me in supporting them in their endeavors in the coming year.

I'd also like to welcome two new board members, Keith Hall and Ted Mastroianni. Keith has been active in raising awareness about the issues faced by adults with TSC and in participating in clinical trials. Ted, who joins us in honor of his grandson Makai, has more than 35 years of experience in the public arena, and offers the organization expertise in management, finance, fundraising and organizational development.

Please join me in also thanking the following board members whose terms are ending this year: Terry Elling, Tommy Lindsey, Rob Thurston and Chris Sheffield. On behalf of the board and our constituents, I take great pleasure in extending my utmost appreciation and gratitude for their commitment and unwavering dedication to guiding the TS Alliance with their expertise. I certainly believe with all my heart that volunteers – whether they serve as board members, Community Alliance leaders or on the local level – are this organization's lifeline. We simply could not move forward without you.

I continue to marvel at the pace of TSC research as we truly are finding better treatments for all TSC individuals, while we continue to search for a cure. This fiscal year, we sponsored our third International TSC Research Conference and instituted a series of free research teleconferences for our constituents on variety of topics. These educational calls have proven to be very popular and allowed the organization to service a large number of our constituency in a very cost-effective manner.

I am very proud of the work our organization has done on behalf of everyone touched by TSC such as my son Matthew, who serves as my daily inspiration. While this is a personal fight for me, I am still humbled by the grace and determination that the members of our community exhibit in facing the daily challenges of this disease. I am taking away so much more than I could possibly give when I read our daily listserv, speak to members of our community and interact with our medical and scientific professionals. But the most important take away I have from the privilege of serving this community is that there is true hope of a cure just around the corner, and I urge all of you to remain steadfastly committed to the TS Alliance's mission of searching for a cure while continuing to improve the lives of all those affected by TSC.

**Celia Mastbaum**

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# My Daughter's TSC Story:

## Triumphing Over Seizures

COVER STORY • BY LISA HALL

*Editor's Note: Jamie Youngblood Holland is 33 years old and has been seizure-free since November 26, 2008. She made the brave decision 18 months ago to undergo brain surgery at the Cleveland Clinic. This is her story about living with tuberous sclerosis complex and coping with seizures.*

As a parent of a child with TSC, it is very painful to endure at times. I can't even imagine how my daughter Jamie felt all those years dealing with the seizures and the drugs. I'm sure anyone reading this can totally identify with us. My daughter was diagnosed at 3 years of age. She was given medications then and still is on Felbatol and Trileptal today.

When the seizures started, she was placed on chewable Dilantin, which controlled her seizures for awhile. Toward the age of 8, we noticed an unusual staring, clapping of hands, and an audible noise I can't describe. They didn't last very long – just a couple of minutes – but afterward, she was always in a state of confusion, remembering nothing. These were complex partial seizures.

With increasing seizures, the medication roller coaster began, and eventually Dilantin stopped working. The complex partials were very difficult to deal with as a teenage girl as the last thing you want to happen is to have a seizure during school. But it definitely happened.

Jamie was never too self-conscious about the seizures. I think because she always participated in every activity you could dream of. She was just like every one else, except she had seizures and took loads of medication



Lisa Hall and her daughter Jamie, one year after surgery.

for it. She was in Girl Scouts and little league softball, went to summer camp for years, played in the band and high school sports, and worked numerous jobs. Her philosophy was, "When I meet new people, I just tell them. I might have a seizure sometimes, but I will be OK in a few minutes."

She had an excellent attitude about the circumstances. However, there were definitely frustrating times. But overall, she functioned in society very well despite the barriers.

At age 19, the grand mal seizures began. The first one was so strong I called an ambulance as I was petrified. Her neurologist suggested seizure surgery evaluation at Johns Hopkins Hospital, in Baltimore, MD. This was in 1996, when she was 20 years old.

She was placed in the epilepsy monitoring unit, taken off meds, and endured test after test. Johns Hopkins put a team together to review her

case after 5 days of collecting data to determine if she was a surgical candidate. At that time, 13 years ago, it was determined to be extremely risky due to the area of the brain where the seizure focus was located: the left temporal lobe, which impacts language and memory function.

The doctors presented their findings to me and to Jamie. Keep in mind, the idea of shaving her head and cutting part of the skull with a surgical saw to remove a section of her brain was not appealing to Jamie at the time. I told her it was her decision. She declined.

From age 20 to 31, she tried every medication under the sun. Dilantin, Depakote, Gabatril, Keppra, Lamictal, Neurontin, Tegratol/Carbartol, Lyrica, and Topamax are some I remember. Presently, she takes Felbatol and Trileptal – half the amount post-surgery than she previously needed. TSC required a combination of medications,

and side effects would vary, including mood swings, weight gain and weight loss. Sometimes they would slow the seizures, and sometimes they didn't phase them.

It was very exasperating for her, living in the adult world and trying to maintain employment was becoming more and more difficult. At age 24, she obtained a job with the Department of Veterans Affairs as a file clerk. I also work at the same campus, so I took her to and from work every day since she could not drive. As her seizures became more frequent, the medication continued to increasingly cause her to live in a constant "fog." Some days were better than others. Bottom line: the meds just didn't work any more.

The near toxic level of medications also slowed her thought processes – even her speech was slower. But still, facing these barriers, she kept going, working and trying to function the very best that she could.

Her seizures had worsened over a 30-year period. It was a slow progression, but the last 10 years had become increasingly dangerous. The grand mal seizures were increasing in number, and the postictal psychosis was horrible. Her neurologist suggested she go for surgery evaluation again since technology and TSC research had advanced tremendously.

It took Jamie several years to finally determine that she'd had enough and was ready to take the risk. She was tired of the emergency calls for an ambulance, the restraints, and injections of valium to stop the postictal psychosis. She became so over-medicated I could not shake her awake in the emergency room. It was terrifying. The final decision was to travel to the Cleveland Clinic. We cannot express how much we loved the people, the doctors, and everything about the Cleveland Clinic. The care was beyond excellent.

Her decision was final. In August 2008 she was admitted to

## It took Jamie several years to finally determine that she'd had enough and was ready to take the risk. She was tired of the emergency calls for an ambulance, the restraints, and injections of valium to stop the postictal psychosis.

the Cleveland Clinic epilepsy monitoring unit as an inpatient for around-the-clock care and video monitoring while all meds were stopped and they did continuous EEG monitoring, CAT scans, PET scans, MRS, and SPECT with injection. After a few days, the seizures were happening quite often, and they recorded enough information to present to the clinical team to determine if she was a surgery candidate. Some of the video was quite gruesome. They attempted to let me see the recordings, but I couldn't watch because of the intensity of the grand mal seizures on no medication. It was not pleasant. The blessing was she never remembered anything. We were there 9 days.

Within a week, we learned she was definitely a seizure surgery candidate, and the team felt very positive they could help her. This was an answered prayer.

The seizure focus was the same as it had been 13 years earlier: the left

temporal region. They had identified the exact spot, but much more detailed testing would be required. We went back on November 16, 2008 with her first surgery scheduled on November 19. This would be to implant electrodes within the brain, 3 on each side, (depth electrodes – 1 was a strip electrode) to monitor from inside the focal area. This involved shaving the sides of her head, drilling holes to implant the electrodes. She was still off of her medication so they could record the seizures from the inside to be absolutely positive where to operate. During this time, horrible seizures were happening. I had never seen a generalized seizure before accept in this controlled environment. The same thing happened during the evaluation in August. It was like a horror movie. It really is not something a mother wants to see. To tell you the truth, I had to leave the room.

The depth electrodes were in for 7 full days. It was a very difficult, emotional, uncomfortable, and painful 7 days. There were days that she begged me to make it stop. I couldn't. I kept telling her, it will all be over soon. That wasn't much to offer, but I was in a stunned state of mind at times. On November 26, 2008, Jamie had a left temporal lobectomy with a resection of the mesial structure and mesial temporal tuber removing the left hippocampus.



Seizure surgery evaluation, August 2008, electrodes in the epilepsy monitoring unit at the Cleveland Clinic.

Jamie and family 28 days after surgery.



There were 3 tubers lined up behind each other. They only detected one with all of the advanced testing, but when the surgeon went in, he said there were two more behind the first one. I believe God used the surgery to give my daughter a new life—a seizure-free life! I am so excited to be a witness!

Jamie has not had a seizure since that day. Her medication is cut in half. She will stay on meds forever, but she no longer lives in a fog. Her recovery and rehabilitation was a lot of hard work for her, but to see her today, you would never know she had serious brain surgery 18 months ago. Her only deficit is reading comprehension and memory issues. Her speech therapist said this will continue to improve in time.

Her doctors said it takes several years for the brain to completely heal itself and reroute to use the memory function on the

right side. She went back to work 3 months after surgery. She drives now. She has a completely new personality. The inner Jamie had been stifled for so many years due to the drugs and trauma of the seizures.

There are so many more details to her story, but I wanted the TSC community to know, there are happy endings. Moms and Dads, be strong for your child, there is hope. Technology is advancing every day. With faith in God—anything is possible. My daughter is living proof. Jamie was married to a wonderful man in May 2007. She works full time, drives herself to and from work now, she can go to Walmart everyday if she wants to! They have a beautiful house with 2 cats...they are her babies. Jamie is very creative. Her yard is full of flowers and not a weed in site. Her new life is a gift from God. I and our family were blessed with seeing her transformation.

## Sibling Chats

The TS Alliance has scheduled Sibling Chats by age groups. Sibling Chats are scheduled for:

<b>June 10</b>	for siblings ages 8-12
<b>June 17</b>	for siblings ages 13-18
<b>June 24</b>	for adult siblings
<b>July 8</b>	for siblings ages 8-12
<b>July 15</b>	for siblings ages 13-18
<b>July 22</b>	for adult siblings
<b>Aug 12</b>	for siblings ages 8-12
<b>Aug 19</b>	for siblings ages 13-18
<b>Aug 26</b>	for adult siblings

*All Sibling Chats start at 7:00 p.m. EDT.*

To participate in these chats just e-mail Dena Hook at [dhook@tsalliance.org](mailto:dhook@tsalliance.org), and she will send you back a confirmation. On the night of the chat you will receive an invitation to the chat and you enter the chat room through this invitation. These chats are closed and can only be entered through an invitation and are monitored for security.

## Adult Topic Calls

The TS Alliance Adult Task Force has set up Adult Topic Calls for May 16 and June 20 at 4:00 p.m. EDT. These calls are for independent or semi-independent adults with TSC. There will be scheduled topics and/or open forums to discuss issues adults have dealing with TSC. For more information on these calls contact Dena Hook at [dhook@tsalliance.org](mailto:dhook@tsalliance.org) or 1-800-225-6872.



# Behaviors and School

If your child is missing school because of his/her behavior and the school's answer is to send him/her home, a behavior evaluation should be performed to address these behaviors. Taking your child out of the learning environment is not addressing his or educational needs. When children are out of school they can't be exposed to the general education curriculum, let alone progress in it, which is a legal requirement under the Individuals with Disabilities Education Act 2004 (IDEA).

When a child is in school and the behavior interferes with his/her learning and/or the learning of others, there should be a formal behavior intervention plan placed in the student's individual education plan (IEP). Since behavior is a common manifestation of individuals with TSC, a functional behavior assessment (FBA) should be done to determine what is triggering the behaviors. A FBA will give much-needed information to develop a positive behavior intervention plan (BIP).

To complete a FBA, information must be gathered to determine what the cause is for the behavior. This information needs to be gathered through:

- Health and medical issues
- Education evaluation testing
- Direct observations (by more than one individual and in different settings)
- Home environment (parents, friends, relatives)

Once information has been gathered the questions to be answered are:

- 1 What behaviors do we want to modify or change?
- 2 Where does the behavior occur?
- 3 In what environment is the behavior occurring?

- 4 What is the common antecedent to the behavior?
- 5 Does there seem to be a pattern?
- 6 What is the trigger (reinforcer) for the behavior?
- 7 Why is the behavior occurring?
- 8 What more appropriate behavior can be taught to replace the inappropriate behavior?

This process cannot be done in an hour and be gathered by one person. There needs to be information gathered in structured and unstructured environments. Parents and medical health professionals should be part of the FBA process to know exactly what is causing the behaviors. When dealing with individuals with TSC, ruling out medical issues first will be of utmost importance. Medications, seizures, and other medical issues must be considered. Sometimes, simple medication changes can have a major effect on behaviors.

## Behavior Intervention Plans

Behavior intervention plans (BIP) must be in writing and placed in the student's IEP. Just talking about putting a BIP in place does not make it happen. If there is a formal plan written and placed on a formal document, then the student is protected under the law. IDEA 2004 includes provisions in the law to protect a student with behaviors that are manifestations of the child's disability.

A BIP should minimize the influences that cause the behavior. It should provide instruction in appropriate behavior to replace the problem behavior and identify accommodation and supports to promote the student's success in social and academic areas. A BIP should be designed to teach social and

problem-solving skills and should also address medical, physical or emotional needs.

Make sure the BIP:

- Is team-developed (including general educator input).
- Is based on the FBA.
- Is in writing and incorporated into the IEP.
- Modifies the antecedents before a behavior can occur.
- Strategies to strengthen and teach appropriate behavior.
- Modifications in curriculum or classroom expectations.
- Provides a crisis intervention plan, if needed.

The purpose of the BIP is to teach appropriate behaviors and keep the student in the school environment so they can be exposed to the general education curriculum and progress in it.

To learn more about FBA and BIP go to [www.tsalliance.org](http://www.tsalliance.org) and click on "For School Issues," then scroll down to publications and choose "Behavior Issues and TSC" to download the publication.



# Sabril (Vigabatrin): Before and After Approval by the FDA

BY DANA HOLINKA

Our daughter Emily, who is now 11 years old, was diagnosed at birth with TSC and was only seizure-free the first three months of her life. By the age of four she was having roughly 35-50 seizures a day. She had been on every anticonvulsant and had the Vagus Nerve Stimulator (VNS) implanted in 2003. We saw improvement with her seizures after the VNS was implanted, but she still had about 20 seizures a day. Without any more options for medication to treat her seizures, the doctors told us we needed to start considering brain surgery for Emily. It was a very difficult time in our lives with no more options and thinking we would have to put our daughter through brain surgery. My first thought was there has to be another drug we can try, or another kind of treatment other than surgery.

While talking to Emily's neurologist about the kind of tests that she would need to do to determine if she was a candidate for brain surgery, he asked if she had ever been on vigabatrin. She hadn't because I always thought it was used only for infantile spasms. I had just assumed that was the case, but her neurologist told us they had been treating individuals with complex partial seizures with vigabatrin and were seeing improvement. I had always heard about the bad side effects of the drug and was really scared.

We decided to give it a try and prayed that this drug would help her. We went home with a prescription for vigabatrin and I called every person I knew whose child was on the drug and got the name of a pharmacy in Canada. I immediately faxed the prescription to them and called them with my credit card number. Within the week we had the tablets in our



Kelsey (left) and Emily Holinka.

hands. We started seeing improvement in her drop attacks as well as her complex partial seizures within the first few weeks. During this time we were told she would have to have a special eye test preformed to see if her vision was being affected by the vigabatrin. We never had the test done because we felt that the improvement in her seizures were more important than the side effects with her vision. The process of adding vigabatrin was very slow and I think we were a little more cautious because the drug was not approved by the Federal Drug Administration (FDA). It took us about a year to get to the level her neurologist recommended.

During that time we continued the process to see if Emily was a candidate for surgery by traveling to many different states to get the most accurate testing completed. Emily's seizures were getting worse. She was having grand mal seizures daily and her drop attacks were the worst we had ever

seen. Vigabatrin was helping, but we had to give her valium on a weekly basis for the seizures and knew we needed to have the surgery as soon as possible.

Emily finally underwent two brain surgeries to separate her corpus callosum. This surgery was a success and got rid of the awful drop attack seizures. Emily is still having about seven complex partial seizures a day but it is an improvement compared to seven years ago. We had talked to her neurologist about taking her off vigabatrin mainly because we were worried about the side effects of her being on it for so long, but he really believes that it is helping her seizures.

Since vigabatrin was approved by the FDA in September 2009, we have continued with the medication. We have worked very closely with her neurologist to get all of the paperwork completed through the SHARE program through Lundbeck Pharmaceuticals in a timely manner. As with any other



drug that is FDA approved, there are many strict policies that both the drug manufacturer and physicians have to follow to continue to supply this drug. One strict guideline that needs to be followed is individuals should have an electroretinogram (ERG) performed every three months. The ERG is a special eye test that is done to see if a person is losing their peripheral vision due to a medication. This is also one of the main reasons the FDA had not previously approved vigabatrin.

We were very excited about the FDA approval of vigabatrin for many reasons. The cost was extremely expensive, and we always worried that the medication would not arrive in time. The pharmacy that we worked with in Canada was very good at calling us to remind us that we needed to refill the prescription, but that was not always the case. During this time I heard many stories of families running out of vigabatrin because of the mail system or circumstances out of their control. With the new SHARE program through Lundbeck Pharmaceuticals families are more at ease in knowing that their medication will be there. The SHARE program has been an effective means for the families to work closely with their child's neurologist in order to get the paperwork required completed in a timely manner. The SHARE program has been excellent and they call to remind us that her prescription needs to be refilled and then they ship it out in time. The only problem that we have come across has been with our own personal insurance company taking care of the co-pay for the medication.

As I mentioned before the regulations regarding the use of vigabatrin requires an ERG test be preformed every three months. I feel it is very important when you call your ophthalmologist office to schedule the ERG test that you state that this test is imperative that your child have as soon as possible to ensure that they remain on this drug to control their seizures, as well as informing them that it will

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There are many strict policies that both the drug manufacturer and physicians have to follow to continue to supply this drug. One strict guideline that needs to be followed is individuals should have an electroretinogram (ERG) performed every three months.

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need to be done every three months. Unfortunately, the ERG machine at our Children's hospital was down for a month for repairs, which delayed the ERG test. During this time I was receiving letters from the SHARE program letting me know that she needs an ERG test done immediately or they might take her off of the vigabatrin. We have completed the ERG and are now working with her neurologist and the ophthalmologist to ensure that the SHARE program receives the proper paperwork that states she has had the ERG completed. If you decide that your child cannot or you do not want to have the ERG test preformed every three months, the neurologist needs to complete the ophthalmologist form and mark the box that says they will not have an ERG test performed. This will have to be completed every three months to ensure that your child will continue receiving vigabatrin.

As a parent of a child with tuberous sclerosis complex we have to make many tough decisions regarding her health on a daily basis. I hope that this article about our journey with Emily has been helpful. Someone asked me today how do I do it and I said, "Well, Emily has only me to survive this disease and I am here to fight it every inch of the way. If there is a medication that I feel will help her have a better quality of life, I will do it!"

### **Lundbeck SHARE Program**

Information about Sabril and resources for healthcare professionals, patients and caregivers can be found at [www.lundbeckshare.com](http://www.lundbeckshare.com).

SHARE is a comprehensive resource for healthcare professionals and their patients with severe or uncontrolled epilepsies, providing:

- The latest clinical and product information from Lundbeck
- Tools and resources to aid patient education
- Specific initiatives to manage permanent vision loss associated with Sabril risk
- Prescription support and restricted distribution
  - Sabril is only available through the SHARE Program due to the risk of permanent vision loss
- Programs to help with patient education and assistance
- Downloadable Seizure Diary

If you have questions regarding medical information or safety of Lundbeck products, call 1-866-209-7604 or send email to [information@lundbeck.com](mailto:information@lundbeck.com).

# Government Advocacy Update



Chris Hawkey, Missy Anderson and Sara Hoey visit with Minnesota Senator Al Franken.

## March on Capitol Hill brings dozens of advocates to Washington, D.C.

On February 24, individuals and families coping with tuberous sclerosis complex (TSC) converged on Capitol Hill to advocate for increased federal funding for TSC. Our advocates held more than 360 meetings with Senators, Representatives and their staff members, urging them to support a \$15 million appropriation for the Tuberous Sclerosis Complex Research Program (TSCRCP) at the Department of Defense. Specifically, we asked our elected officials to sign onto bipartisan “Dear Colleague” letters that were circulated by Representatives Loretta Sanchez (D-CA) and Gary Miller (R-CA) in the House and Senators Sherrod Brown (D-OH) and Mike Crapo (R-ID) in the Senate. Our advocates shared their personal stories with their Members

of Congress and clearly explained how greater federal investments in research can lead to new breakthroughs in our understanding of this complex disorder!

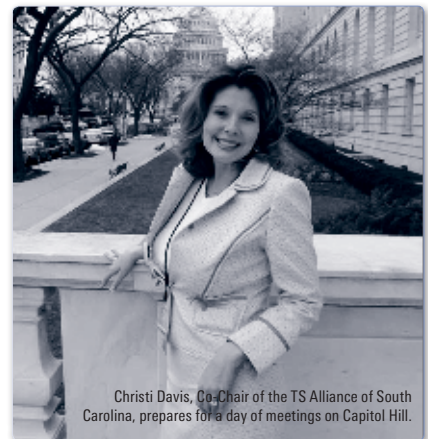
## House and Senate Dear Colleague letters attract strong support from Members of Congress

Thanks in large part to our March on Capitol Hill, the Sanchez-Miller letter attracted the support of 90 members of the House of Representatives – a record number of signatures for this annual letter. In the Senate, the Brown-Crapo letter was signed by 22 Senators, exceeding last year’s number of signatures. The House letter was sent to the House Appropriations Subcommittee on Defense on March 22, and the Senate letter was submitted to the Senate Appropriations Subcommittee on Defense on April 8. The House and

Senate Appropriations Committees are expected to act on the fiscal year 2011 Defense Appropriations bill in the coming months.

Although both House and Senate letters attracted a strong level of support, they do not by any means guarantee that the TSCRCP program will receive an increase in funding above the \$6 million appropriated in fiscal year 2010. The huge federal budget deficit will make it very difficult for Congress to approve any increase in funding for any federal programs. However, our advocacy efforts demonstrate a strong level of grassroots commitment to finding a cure for TSC, and it is our hope that Congress will respond with an increase in funding!

Our efforts could not have been possible without our champions in Congress who worked hard to secure support from their colleagues for these letters. Of course, this successful effort would have not been possible without the dedication of our advocates around the country who took the time to come to Washington, D.C. or who met with their elected officials back home.



Christi Davis, Co-Chair of the TS Alliance of South Carolina, prepares for a day of meetings on Capitol Hill.



# TSCR Letter

## Senate Cosigners

### CALIFORNIA

Barbara Boxer

### CONNECTICUT

Christopher Dodd

Joseph Lieberman

### GEORGIA

Saxby Chambliss

Johnny Isakson

### HAWAII

Daniel Akaka

### IDAHO

Mike Crapo

Jim Risch

### ILLINOIS

Roland Burris

Richard Durbin

### MICHIGAN

Debbie Stabenow

### NEW HAMPSHIRE

Jeanne Shaheen

### NEW JERSEY

Frank Lautenberg

Robert Menendez

### NEW YORK

Kirsten Gillibrand

Charles Schumer

### OHIO

Sherrod Brown

### OREGON

Jeff Merkley

Ron Wyden

### PENNSYLVANIA

Robert Casey

### RHODE ISLAND

Sheldon Whitehouse

### SOUTH DAKOTA

Tim Johnson

## House Cosigners

### ALABAMA

Artur Davis (AL-7)

### ARKANSAS

Vic Snyder (AR-2)

### ARIZONA

Raul Grijalva (AZ-7)

### CALIFORNIA

Henry Waxman (CA-30)

Judy Chu (CA-32)

Laura Richardson (CA-37)

Gary Miller (CA-42)

Joe Baca (CA-43)

Loretta Sanchez (CA-47)

### CONNECTICUT

Joe Courtney (CT-2)

Rosa DeLauro (CT-3)

Jim Himes (CT-4)

Christopher Murphy (CT-5)

### FLORIDA

Alcee Hastings (FL-23)

Kathy Castor (FL-11)

### GEORGIA

Hank Johnson (GA-4)

John Lewis (GA-5)

David Scott (GA-13)

### HAWAII

Mazie Hirono (HI-2)

### ILLINOIS

Bobby Rush (IL-1)

Luis Guterrez (IL-4)

Melissa Bean (IL-8)

Janice Schakowsky (IL-9)

### INDIANA

Andre Carson (IN-7)

Brad Ellsworth (IN-8)

### IOWA

Bruce Braley (IA-1)

David Loebsack (IA-2)

Leonard Boswell (IA-3)

### KANSAS

Dennis Moore (KS-3)

### MASSACHUSETTS

James McGovern (MA-3)

Barney Frank (MA-4)

Stephen Lynch (MA-9)

William Delahunt (MA-10)

### MARYLAND

Chris Van Hollen (MD-8)

### MAINE

Chellie Pingree (ME-1)

Michael Michaud (ME-2)

### MICHIGAN

Dale Kildee (MI-5)

Mark Schauer (MI-7)

Gary Peters (MI-9)

Sander Levin (MI-12)

John Conyers (MI-14)

### MINNESOTA

Keith Ellison (MN-5)

Collin Peterson (MN-7)

James Oberstar (MN-8)

### MISSOURI

Russ Carnahan (MO-3)

### NORTH CAROLINA

David Price (NC-4)

Brad Miller (NC-13)

### NEW MEXICO

Martin Heinrich (NM-1)

### NEW JERSEY

Chris Smith (NJ-4)

Frank Pallone, Jr. (NJ-6)

Bill Pascrell, Jr. (NJ-8)

Rush Holt (NJ-12)

### NEW YORK

Pete King (NY-3)

Carolyn McCarthy (NY-4)

Gregory Meeks (NY-6)

Joseph Crowley (NY-7)

Jerrold Nadler (NY-8)

Edolphus Towns (NY-10)

Carolyn Maloney (NY-14)

Eliot Engel (NY-17)

William Owens (NY-23)

Dan Maffei (NY-25)

Chris Lee (NY-26)

### OHIO

Steve Driehaus (OH-1)

Charles Wilson (OH-6)

Marcia Fudge (OH-11)

Betty Sutton (OH-13)

John Boccieri (OH-16)

### OREGON

David Wu (OR-1)

Peter DeFazio (OR-4)

### PENNSYLVANIA

Robert Brady (PA-1)

Jason Altmire (PA-4)

Jim Gerlach (PA-6)

Joe Sestak (PA-7)

Patrick Murphy (PA-8)

Christopher Carney (PA-10)

Charles Dent (PA-15)

Tim Holden (PA-17)

### SOUTH DAKOTA

Stephanie Herseth

Sandlin (SD-At Lrg)

### TENNESSEE

Steve Cohen (TN-9)

### TEXAS

Ron Paul (TX-14)

Sheila Jackson Lee

(TX-18)

Charles Gonzalez (TX-20)

### VIRGINIA

Robert Scott (VA-3)

### WASHINGTON

Rick Larsen (WA-2)

Jim McDermott (WA-7)

### WISCONSIN

Tammy Baldwin (WI-2)

Thomas Petri (WI-6)

Steve Kagen (WI-8)

### GUAM

Madeleine Bordallo

(Guam-At Lrg)

## TS Alliance Staff Contact Information

All staff can be contacted by email or by calling the office toll-free phone number: (800) 225-6872. Staff members are available for assistance in finding resources and/or to answer any questions you may have. Note: To email a staff member, use First Initial Last Name @tsalliance.org or Info@tsalliance.org.

### Kari Luther Carlson

President and Chief Executive Officer

### Gail Alexander

Senior Manager of Operations

*Executive support and oversight of office operations*

### Tyler Hoffman

Development Coordinator

*Development support*

### Dena Hook

Director of Advocacy and Education

*Constituent support and advocacy, community outreach and educational initiatives*

### Jaye Isham

Senior Director of Marketing and Communications

*Strategic communications and marketing, media relations and online strategy oversight*

### Jo Anne Nakagawa

Director of Clinical Projects

*Development and implementation of the TSC Clinical Database Project and TSC clinics liaison*

### Mary Jane Perraut

Controller

*Financial management and oversight*

### Jenny Smiley

Director of Community Outreach

*Volunteer program and special events oversight*

### Katie Smith

Science Coordinator

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### Bronia Svoisky

Staff Accountant

*Accounting support*

### Dee Triemer

Community Outreach Manager

*Volunteer management and support*

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Vice President and Chief Scientific Officer

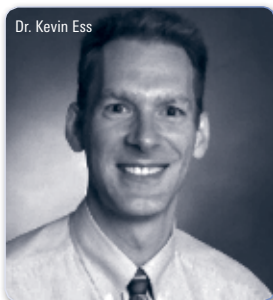
*Scientific affairs and medical outreach*

# TSC Clinics "Up Close"

**T**he Tuberous Sclerosis Alliance recognizes 27 medical practices in the U.S. that provide coordinated specialty care to persons with TSC through their clinic or through a network of referrals. Each TSC Clinic is directed by a licensed physician who holds a medical specialty certification, generally in a subspecialty related to a TSC-related condition. This article continues a series about these TSC Clinics with an introduction to the healthcare professionals who staff them and highlights about the clinics.

## The Tuberous Sclerosis Clinic at Washington University – St. Louis, MO

The TS Clinic at Washington University opened in 2002 under the direction of Kevin C. Ess, M.D., Ph.D., a child neurologist and researcher at Washington University (WUSTL) with a special interest in tuberous sclerosis complex (TSC). The TS Clinic is open to children with TSC and is located at the St. Louis Children's Hospital. When Dr. Ess moved to Vanderbilt University in 2006, Michael Wong, M.D., Ph.D. agreed to take over as the TSC Clinic Director. Dr. Wong is assisted by Administrative Coordinator Laura Graves; Nurse Coordinator Christine Immken, R.N., C.P.N.; and Community



Dr. Kevin Ess

Alliance Volunteer René Friedel, who provides social education and support from the perspective of a parent with a child affected by TSC.

### Mice with TSC and Seizures

Dr. Wong's interest in TSC came about serendipitously when Dr. Ess' research mentor and TS Alliance-funded researcher, Dr. David Gutmann, noticed that the mouse model of TSC he was studying also had seizures. Knowing that Dr. Wong was doing epilepsy research, he approached him with a proposition, "I've got mice with TSC who are having seizures... are you interested?" Nearly a decade later, Dr. Wong is recognized as one of the leading TSC researchers using the mouse model of TSC to better understand what causes epilepsy in humans and how to treat it. He and other TSC researchers are working toward unlocking the mysteries of TSC to find a cure.

### A "Clinic Without Walls" Model

Dr. Wong describes his clinic as being similar to the "clinic without walls" model, which Dr. Michael Frost conceived for his TSC clinic in St. Paul, Minnesota. He, like Dr. Frost, is board-certified in child neurology and clinical neurophysiology. Dr. Wong thinks of his role as a "gatekeeper" for children affected by TSC by offering a more efficient, comprehensive, and coordinated approach for screening and evaluating individuals with TSC than a primary care practice. Those individuals with non-neurological issues

are referred to colleagues within the WUSTL/Children's network of affiliated healthcare providers.

### Bench Side to Patient Care

Dr. Wong has a unique perspective in seeing the disease of TSC from the research he conducts in his laboratory as well as in his TSC clinic where he sees how individuals with TSC are affected. His clinic follows about 75 individuals with TSC. Sometimes the wait list to get an appointment in the TSC Clinic may be up to 3 months, but if it's medically necessary an appointment is scheduled in Dr. Wong's epilepsy clinic so they are seen sooner. His nurse, Christine, shares an insight into how much he cares about his patients, "Dr. Wong takes all the time the individual with TSC and their family needs to spend during their appointment." In order to maximize this doctor-patient time, his office requests that medical records be sent to him to preview in advance of their appointment.

### Dual Role for a Clinical Nurse Coordinator

Christine Immken, R.N., C.P.N. has been in nursing for 10 years, with most of it spent in neurology and pediatric epilepsy. She is the Clinical Nurse Coordinator for the Epilepsy Unit and recently assumed the additional role of coordinator of the TSC Clinic. The WUSTL pediatric neurology office triages TSC-related telephone calls to her and she is with Dr. Wong at the monthly clinic appointments. She prepares for each clinic by reviewing the patient's last visit, last phone notes, current



medications, and also reviews whether or not they are due for a follow-up brain MRI, renal ultrasound, or other diagnostic test, so that these tests can be coordinated with the appointment to “save them another trip to the hospital if possible!”

## The Community Alliance Partnership

One of the ongoing goals of the TS Alliance is to strengthen the relationship between the Community Alliances and the TSC clinics. René Friedel, the mother of a child with TSC and currently the Chair of the TS Alliance of St. Louis & Southern Illinois, began to build a solid relationship between the local volunteer branch and the WUSTL TS Clinic shortly after it opened by collaborating with Dr. Ess to initiate a TSC outreach program at the clinic. With his support (and later Dr. Wong’s) and by going through the Children’s Hospital Volunteer Program, she has volunteered hundreds of hours to provide families with “calmness, hope

and positive feedback and in addition, information about what the TS Alliance does locally and nationally.” Dr. Wong values her dedication to the program and considers it one of the special services that their clinic is able to provide to individuals with TSC and their families.

“I am very proud to be working with Dr. Wong and Christine,” says René. She recounts a remarkable experience that happened when she wondered if she was making a difference to anyone. During one clinic, she met with a family who lived in a very rural area. She talked for about an hour with the mother who was very despondent about the future for her 6-month old with TSC. About 8 months later this mother passed René in the hospital corridor and smiled at her and asked if she remembered her. René recalled how wonderful she looked compared to the time when they talked in clinic. The mother told her how grateful she was for the hope and new perspective she gave to her.

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Dr. Wong thinks of his role as a “gatekeeper” for children affected by TSC by offering a more efficient, comprehensive, and coordinated approach for screening and evaluating individuals with TSC than a primary care practice.

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For more information about the TS Clinic at Washington University call (314) 454-6120 and speak with Christine Immken, R.N., C.P.N.



L to R: Laura Graves, Michael Wong, M.D., Ph.D., Christine Immken, R.N., C.P.N., René Friedel

# Research Update:

## Biomarkers for TSC and LAM

Recent research from investigators at Cincinnati Children's Hospital Medical Center shows that a substance in the blood may be useful in the diagnosis of women with sporadic lymphangioleiomyomatosis (S-LAM) and for those with LAM associated with tuberous sclerosis complex (TSC). These investigators found that a serum VEGF-D level of greater than 800pg/ml in a woman with typical cystic changes on high resolution CT (HRCT) is diagnostically specific for S-LAM and identifies LAM in women with TSC. A negative VEGF-D result does not exclude the diagnosis of LAM. The utility of serum VEGF-D testing in males or in women who do not have cystic lung disease on HRCT is unknown.

Why is this important and what is a biomarker? A **biomarker**, or **biological marker**, is defined by the National Cancer Institute, National Institutes of Health, as a biological molecule found

in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. A biomarker can be used as an important tool to use in clinical care of individuals and/or to study the response to a specific treatment in clinical trials instead of using imaging or other expensive tools.

The best known example of a biomarker is the prostate-specific antigen (PSA) that is an indicator of the presence of prostate cancer in men. PSA is a protein produced by cells of the prostate gland and is measured by testing the levels of PSA in the blood. Recently, studies have shown that the level of PSA in the blood does not always correlate with presence of cancer and/or the progression of disease, but reduction in the level of PSA in men being treated for prostate cancer is a good biomarker for the response to treatment.

If there were reliable and accurate biomarkers for TSC and LAM, it would be possible to diagnosis TSC and/or LAM through a blood test, as well as to measure the progression of the disease as well as response to treatment through a blood test. Today, expensive imaging studies are required to look at reduction of the size of tumors in the brain, kidney and lungs in response to treatment. VEGF-D may become a good biomarker for individuals with LAM, but further research will be needed to see if it will be a reliable biomarker in men and for other manifestations of TSC besides lung involvement or LAM.

This research was published by Young LR, Vandyke R, Gulleman PM, Inoue Y, Brown KK, Schmidt LS, Linehan WM, Hajjar F, Kinder BW, Trapnell BC, Bissler JJ, Franz DN, McCormack FX (2010) Serum vascular endothelial growth factor-D prospectively distinguishes lymphangioleiomyomatosis from other diseases. Chest 2010 April 9 [Epub ahead of print].

## Lids Store Embroidery Benefits the TS Alliance

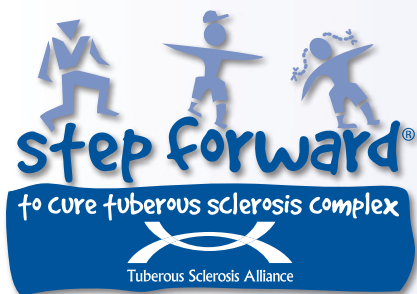
Throughout the rest of 2010, visit any LIDS Store that offers custom embroidery to show your support for having the official TS Alliance logo embroidered on a hat for \$9.00. To help support our cause, LIDS will donate the full \$9.00 to the TS Alliance.

To get the special flyer, visit [www.tsalliance.org](http://www.tsalliance.org) and look under "Special Announcements" on the home page. You can also visit [www.lids.com/locations](http://www.lids.com/locations) to find store sites that offer their custom embroidery services. If you have questions, contact Jenny Smiley at (800) 225-6872.





# Upcoming Major Events



## TS Alliance of the Carolinas

**October 2, 2010**

Lake Murray Dam, Lexington, SC  
Christi Davis; thechristi75@hotmail.com

## TS Alliance of Delaware/Lehigh Valley

**September 25, 2010**

Gring's Mill, Wyomissing, PA  
Shelly Richards; mom2ashlin@yahoo.com

## TS Alliance of Florida

**October 23, 2010**

Crandon Park, Key Biscayne FL  
Vanessa Vazquez; VanessaVazquez@bellsouth.net

## TS Alliance of Heartland

**October 16, 2010**

Raccoon River Park, W. Des Moines, IA  
Cindy & Ryan Blackard; cblackard@yahoo.com

## TS Alliance of Metro DC

**Date: TBD**

Plaza in downtown Silver Spring, MD  
Nathalie Simoneau; yvesnat@verizon.net

## TS Alliance of Middle Tennessee

**October 16, 2010**

Centennial Park Event Shelter, Nashville, TN  
Amy Hobbs; amyghobbs@aol.com

## TS Alliance of New York & New Jersey

**September 11, 2010**

Onondaga Lake Park, Liverpool, NY  
Stephanie Langstaff; sclangst@syr.edu

**September 25, 2010**

Wantagh Park, Wantagh, NY  
Denise & Rob Spear; rspear96@gmail.com

New Jersey – TBD

James Richter; jrichter@winston.com

## TS Alliance of Northern California

**Date: TBD**

Sacramento, CA  
Suki Maharaj; sukimaharaj@hotmail.com

## TS Alliance of Ohio

**September 26, 2010**

Roman Park, Westlake, OH  
Michelle Blood; bblood@aol.com

## TS Alliance of Wisconsin

**Date: October 2, 2010**

Grant Park, S. Milwaukee, WI  
Pam Sztukowski; pamchef@wi.rr.com

## National Presenting Sponsors



## National Honorary Chair – Julianne Moore



## Find Out More Online

Go to [www.StepForwardtoCureTSC.org](http://www.StepForwardtoCureTSC.org) to register for a walk in your area and be sure to check out all our new online walker tools, like sample emails to help you raise money, team leader kits, walker participation packets and much more.

## Organize a Walk in Your Community

Find out how you can stage a Step Forward to Cure TSC event in your local area by contacting Jenny Smiley at (800) 225-6872 or [jsmiley@tsalliance.org](mailto:jsmiley@tsalliance.org).

# TSC Drug Screening Program:

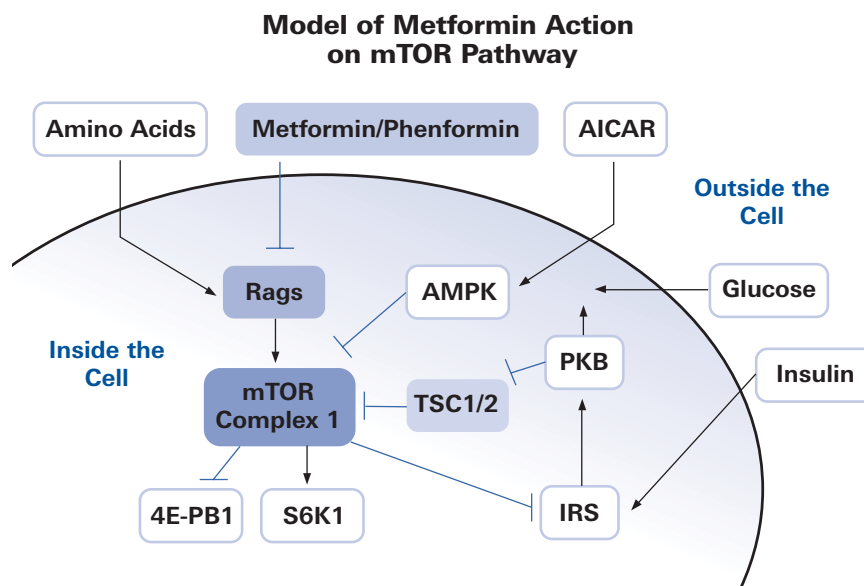
## Potential for New Treatments for TSC

Thanks to the generous support from The Cowlin Family Fund and the Robertson Foundation, the TS Alliance is implementing a new TSC Drug Screening Program. This program is designed to fast-track potential new treatments for TSC from the laboratory into testing in animal models of TSC and into clinical trials. The pharmaceutical industry calls this the drug pipeline that goes all the way from the initial idea to test a compound or a drug, through the animal testing to make sure it is safe and effective in model systems of TSC, and then through clinical trials and eventually and hopefully approval by the Federal Drug Administration. From beginning to end, this process can take up to 15 years and cost more than \$15 million – for just one drug! However, the process is in place to make sure that drugs that are approved by the FDA are safe and effective for the indication they are approved for.

Currently, the TS Alliance is reviewing applications for the TSC Drug Screening Program and the new awards will be announced in July 2010. There are many ideas for testing already FDA-approved drugs in TSC model systems, as well as new compounds that are in development.

Two new avenues of research that are being tested in TSC model systems are:

**1** A recent report showed the medication metformin, an FDA-approved drug for the treatment of type 2 diabetes, may be helpful in treating TSC, but it has a different mechanism of action than was previously understood. Rather than acting directly on the protein mammalian target of rapamycin (mTOR), metformin



**4E-PB1** = Initiation Factor 4E-Binding Protein 1  
**AICAR** = 5-aminoimidazole-4-carboxamide-1-β-D-ribofuranoside  
**AMPK** = AMP-activated Kinase  
**IRS** = Insulin Receptor Substrate Family  
**mTOR** = mammalian target of rapamycin

**PKB** = Protein Kinase B (AKT)  
**Rag proteins** = Family of four related small guanosine triphosphatases (GTPases)  
**S6K1** = S6 Kinase 1  
**TSC1/2** = Tuberous Sclerosis Complex proteins 1 and 2

works through a different pathway (see the diagram modified from Kalendar et al., 2010). This may be another potential treatment for TSC.

**2** Glutamate is an amino acid that is found throughout the body, but is especially important as an excitatory neurotransmitter in the brain. Many companies are developing drugs that block the action of glutamate, which may be especially important in epilepsy and for some forms of intellectual disability. A recent *New York Times* article described the use of this class of compounds to treatment Fragile X, and a 2009 study also tested this class of drugs in a pilot trial. TSC research in this area is focused on

identifying whether or not these drugs might also be beneficial in animal models of TSC where seizures are prominent, as well as for learning, memory and other cognitive issues.

## References

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- Berry-Kravis E, Hessel D, Coffey S, Hervey C, Schneider A, Yuhás J, Hutchinson J, Snape M, Tranfaglia M, Nguyen DV, Hagerman R (2009) A pilot open label, single dose trial of fenobam in adults with fragile X syndrome. *J Med Genet* 46(4):266–71.



## Honorariums (January – March 2010)

You can honor a friend or family member for an important occasion with a gift to the TS Alliance. It is a wonderful way to send a birthday or anniversary wish, or congratulations for retirement, a job well done, graduation, etc. Please include the name and address of the individual being honored so that acknowledgement of your kind donation can be sent. Tuberous Sclerosis Alliance honorarium cards are also available if you would like to make a gift in honor of family, friends, or colleagues. To receive tribute cards, call Tye Hoffman at (800) 2258-6872 or by email at [thoffman@tsalliance.org](mailto:thoffman@tsalliance.org). In addition you can also create your fundraising page in honor of a special occasion at [www.tsalliance.org](http://www.tsalliance.org).

**Tribute(s) for Joan Abramson**  
Mr. and Mrs. Robert Hockstein

**Tribute(s) for Daniel Beldner**  
Ms. Martha Koven  
Mr. Michael Schoenbaum and Ms. Elisa Rapaport

**Tribute(s) for Matthew Beyer**  
Mr. Michael McClusky and Ms. Lisa A. Beyer

**Tribute(s) for Jacob Blood**  
Mr. and Mrs. James Manco

**Tribute(s) for Dante S. Buccudu**  
Mr. Sergio Carranza

**Tribute(s) for Julianne Calvano**  
Stop and Shop

**Tribute(s) for Matty Campbell**  
Mr. Thomas V. Kavanagh

**Tribute(s) for Mary Ciliberte**  
Mr. and Mrs. Ernest Acosta

**Tribute(s) for Dane Dawson**  
Ms. Laura Auclair  
Ms. Emily Schwab  
Mr. Scott Singer  
Ms. Susan L. Singer

**Tribute(s) for Cole Denharder**  
Mr. and Mrs. Ron Oakes

**Tribute(s) for Reiko Donato**  
Lawrence Smith Foundation

**Tribute(s) for Kierstin Dublinske**  
Mr. and Mrs. M. Bruck

**Tribute(s) for Jude W. Ebel**  
Mr. and Mrs. Dale Ebel

**Tribute(s) for Preston Fitzgerald**  
Ms. Carla Carr  
Mr. and Mrs. Robert C. Fitzgerald

**Tribute(s) for Sophia Flicker**  
Ms. Sandra K. Flicker  
Ms. Nancy Heim

**Tribute(s) for Gerald Friedman**  
Mrs. Ina Goldstein

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Mr. Paul Abramson  
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Ms. Pam Simon

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Dr. John C. Hulbert and Dr. Alice Hulbert

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Mr. and Mrs. Stanley Worton  
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Ms. Patricia Ogden

**Tribute(s) for Anna Koponen**  
Mr. JD Holland  
Ms. Magdalena Schneider

**Tribute(s) for Jacob Koponen**  
Mr. JD Holland

Ms. Magdalena Schneider

**Tribute(s) for Jackson Kozisek**  
Mr. and Mrs. Joan Gohn

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Mr. Roland Wigham

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Mr. and Mrs. Tom Doherty

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Mr. and Mrs. Mel Roberts  
Ms. Sheila Schlaggar  
Mr. and Mrs. Marc Schulhof  
Ms. Paula D. Segal  
Mr. Harold Shansky  
Mr. and Mrs. George Victor  
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**Tribute(s) for Haley N. Lynch**  
Mr. and Mrs. Jerry Short

**Tribute(s) for Sheila Marton**  
Mrs. Barbara F. Zimmerman

**Tribute(s) for Jacob C. Matthews**  
Mr. and Mrs. Arthur L. Fisher

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Mrs. Melissa Rinacke

**Tribute(s) for Louise McClure**  
Mr. and Mrs. Marion S. Adams, Jr.

**Tribute(s) for Ashlin McFadden**  
Ms. Amanda Vroom

**Tribute(s) for Megan McGehee**  
Mr. and Mrs. Marion S. Adams, Jr.

**Tribute(s) for Colin McKiernan**  
Ms. Missy McKiernan

**Tribute(s) for Lindsay Moody**  
Ms. Ashley Gilbert

**Tribute(s) for Olivia Murray**  
Mr. Thomas W. Larsen

**Tribute(s) for Lauren Niemeyer**  
Kristina Niemeyer

**Tribute(s) for Richard Overbey**  
Mr. and Mrs. Marion S. Adams, Jr.

**Tribute(s) for William F. Pfeiffer**  
Mrs. Kay Peters

**Tribute(s) for Will Piotrowski**  
Ms. Mary Barber  
Mr. and Mrs. William K. Carruth

**Tribute(s) for Jack Poutasse**  
Dr. and Mrs. William Flynn Jr.  
Ms. Linda Guly  
Mr. Eric Korenman and Ms. Marianna Poutasse  
Mrs. Katarina Orkand

**Tribute(s) for Faith Rentar**  
Mr. Rick Douglas

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Mrs. Mary Ellen Zappia

**Tribute(s) for Lillian Rose**  
Mr. Gerald Dowd  
Ms. Carrie Jadud  
Mrs. Shelby Van Voris-Schoenborn

**Tribute(s) for Grace Rubeck**  
Mr. and Mrs. Tyler Stevenson

**Tribute(s) for Anna Russell**  
Mr. and Mrs. Valentine J. Pust

**Tribute(s) for Emmory Shapses**  
Mr. and Mrs. Marc Shapses

**Tribute(s) for Madalyn Scherer**  
Mr. and Mrs. Michael Schneider

**Tribute(s) for Carter Schmidt**  
Ms. Amy L. Fox

**Tribute(s) for Greyson R. Schwaigert**  
Mrs. Lindsey Hamilton

**Tribute(s) for Kylie Seggerman**  
Ms. Nadine A. Klemens-Gilmore

**Tribute(s) for Benjamin Shapiro**  
Mrs. Caroline Kunitz  
Mrs. Trish Modabber

**Tribute(s) for Henry P. Shapiro**  
Mr. Simon Groner

**Tribute(s) for Drew Sklarin**  
Mr. and Mrs. Larry Donsky

**Tribute(s) for Olivia Smiley**  
Insulation Products Corp

**Tribute(s) for Lillian R. Solise**  
Mrs. Erika Jones  
Anonymous

**Tribute(s) for Suzanne Stoll**  
Mr. and Mrs. Paul A. Schumacher

**Tribute(s) for Emily B. Szilagyi**  
Mr. and Mrs. Jerome Aroesty  
Mrs. Diane Burgess  
Dr. and Dr. Malin Dollinger  
Ms. Sandra A. Edwards  
Mrs. Linda C. Ellrod  
Mr. and Mrs. Reiner Lagraff  
Mr. Greg Lenthén  
Mrs. Malka Lilienthal  
Mr. and Mrs. Larry Meyers  
Dr. Eric Small

**Tribute(s) for Chandlee Taylor**  
Mr. and Mrs. Kevin R. Coneys

**Tribute(s) for Makenna G. Turner**  
Mr. and Mrs. Harold C. Podgorski

**Tribute(s) for Kurt T. Ullrich**  
Ms. Anita Ullrich

**Tribute(s) for Ryan Ventimiglia**  
Washington Street School

**Tribute(s) for Eli Warner**  
Mr. and Mrs. Thomas E. Howie

**Tribute(s) for Addilyn Wenger**  
Mrs. Karen Johnson-Wenger

**Tribute(s) for Kalla E. Windham**  
Ms. Donna G. Howard

## Memorials (January – March 2010)

Contributions are given to the Tuberous Sclerosis Alliance at the request of family members in memory of their loved ones. We extend our sympathies to the family and friends of those memorialized below. These generous contributions support the progress of our mission to find a cure for tuberous sclerosis complex.

**Tribute(s) for John A. Alukonis**  
Mr. and Mrs. David Brahm  
Mr. William Kamienik  
Mr. and Mrs. Kenneth Toki

**Tribute(s) for Harold L. Aronson**  
Ms. Melinda Snyder

**Tribute(s) for Bernard Beem**  
Mrs. Heidi Anderson

**Tribute(s) for Celia Burack**  
Mrs. Naomi Childers  
Mr. and Mrs. Stanley Worton

**Tribute(s) for Mary B. Ciliberti**  
Mr. Ronald Sironen

**Tribute(s) for Winnie Counts**  
Mr. and Mrs. Marion S. Adams, Jr.

**Tribute(s) for Cecile Crowell**  
Ms. Genevieve M. Carter  
Classic Cuts  
Mr. and Mrs. Theodore J. Crowell  
Mr. and Mrs. Glenn A. Foster  
Ms. Peggy A. Gettys  
Mr. and Mrs. David L. Roy  
Mr. and Mrs. Wilfred J. Roy  
Ms. Sandy Weston

**Tribute(s) for Sylvia Cushing**  
Mr. and Mrs. Marion S. Adams, Jr.

**Tribute(s) for Richard Denton**  
Mrs. Sue Bennett  
Ms. Virginia T. Chapman and Ms. Diane Chapman  
Mr. Anthony Mazzamuto

**Tribute(s) for Cork Enslin**  
Mr. and Mrs. Gerald E. Enslin

**Tribute(s) for Heidi Erb**  
Mr. and Mrs. Robert E. Gendreau

**Tribute(s) for Rose Glanzberg**  
Mr. and Mrs. Mel Chaifetz

**Tribute(s) for Henry Grider**  
Ms. Mary Alice Goble

**Tribute(s) for Hubert Hensley**  
Ms. Frances I. Paden

**Tribute(s) for Joseph Herman**  
Mr. and Mrs. Robert Hockstein

**Tribute(s) for Thomas W. Kelty**  
Mrs. Judy Bostwick

**Tribute(s) for Mark Luebbe**  
Mr. and Mrs. Rodney J. Weeks

**Tribute(s) for Michael Mac Ginley**  
Mr. Daniel Doyle

**Tribute(s) for Michael MacGinley**  
Mrs. Mary Kennedy  
Mr. and Mrs. Daniel MacGinley  
Dr. William Tatum  
Mrs. Betty Truncale

**Tribute(s) for Elizabeth Nelson**  
Mr. Greg Linsin and Ms. Julie A. Blum  
Ms. Kari Luther Carlson  
Mr. Ted DeBraga  
Ms. Alice Easterling  
Mr. and Mrs. Frederick E. Fisher  
Dr. Elizabeth P. Henske  
Mr. and Mrs. Abe Mastbaum  
Ms. Eva Monastersky  
Ms. Mary Rouse

**Tribute(s) for Rita Okun**  
Mr. and Mrs. Robert Hockstein

**Tribute(s) for Soleil L. Pilgrim**  
Mr. Jim Ham and Ms. DJ Pace

**Tribute(s) for Lydia Quinones**  
PC Doctors of Tamarac

**Tribute(s) for Frank J. Reilly**  
Mr. Andrew Hunter

**Tribute(s) for Carson Russell**  
Mr. and Mrs. Richard E. Allen  
Ms. Phyllis Atkinson  
Ms. Shelley Boyd  
Mr. and Mrs. Charles D. Brigham  
East Haven Police Union  
Mr. Michael Fitzpatrick  
Mr. and Mrs. Kevin Foote  
Ms. Judi Fouchet  
Mrs. Lee Ann Gamble  
Mrs. Catherine Gazikas  
Gem Environmental  
Mrs. Kristi Hopper  
Mr. and Mrs. Maurice Keane  
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Mr. and Mrs. Chris Russell  
Mr. Bruce Scobie  
Ms. Gloria Shirvell  
Mrs. Barbara Siegel  
Southold Voice, Inc  
Mr. Nicholas S. Tsounis

**Tribute(s) for Chris N. Stamulis**  
Mrs. Kristin Beddoe  
Mr. and Mrs. Jim Burns  
Mr. and Mrs. Robert C. Childers  
Ms. Helen Everhart  
Ms. Ruth C. Feldewerth  
Ms. Joan James  
Mr. and Mrs. John N. Jouriles  
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Mr. and Mrs. Pete J. Sallas

Mr. and Mrs. James T. Shelton

**Tribute(s) for Haley Stovall**  
Ramey, Inc  
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Mr. and Mrs. Gerald Jette  
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Mr. and Mrs. Edmund Olszewski  
Ms. Catherine R. Rice  
Ms. Dorothy J. Salmonson

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Mr. and Mrs. Joan Gohn

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Mrs. Amy Ballar  
Ms. Jane Fox  
Mr. and Mrs. J. David Fraley  
Mr. and Mrs. Jack G. Gray  
Mr. and Mrs. David Johnson  
Ms. Mary L. Patterson and Ms. Susan M. Anderson  
Mr. and Mrs. Tim Straubel  
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**Tribute(s) for Kathleen Williams**  
Ms. Tracy Wilson

**Tribute(s) for Margaret M. Williams**  
Mr. and Mrs. Glen A. Call  
Mr. and Mrs. John G. Fordney

# Recommended Reading

## Out of My Mind

by Sharon M. Draper



### Synopsis:

Eleven-year-old Melody has a photographic memory. Her head is like a video camera that is always recording. Always. And there's no delete button. She's the smartest kid in her whole school but no one knows

it. Most people her teachers and doctors included don't think she's capable of learning, and up until recently her school days consisted of listening to the same preschool-level alphabet lessons again and again and again. If only she could speak up, if only she could tell people what she thinks and knows . . . but she can't, because Melody can't talk. She can't walk. She can't write.

Being stuck inside her head is making Melody go out of her mind that is, until she discovers something that will allow her to speak for the first time ever. At last Melody has a voice . . . but not everyone around her is ready to hear it.

## Think College! Postsecondary Education Options for Students with Intellectual Disabilities

by Meg Grigal, Debra Hart

**Synopsis:** As the Higher Education Opportunity Act opens the door to more options and supports, more and more students with intellectual disabilities are

"thinking college."

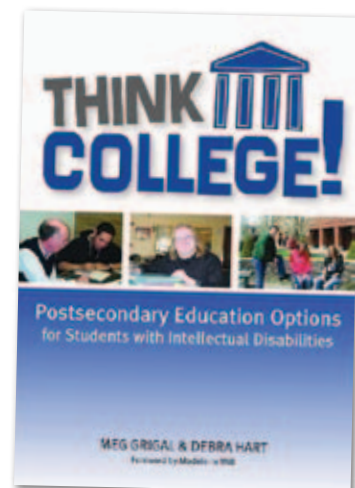
That means high schools, colleges, and universities must be fully prepared to meet the needs of students with disabilities—and this comprehensive resource is just what they need. Developed by two of the most respected experts on this hot topic, this book uncovers the big picture of today's postsecondary options and reveals how to support students with disabilities before, during, and after a successful transition to college.

A critical resource for education professionals to read and share with families, *Think College* helps readers

- understand the three current models for postsecondary education (PSE): inclusive individual supports; substantially separate, noninclusive classes; and hybrid approaches
- overcome the common challenges and barriers to PSE for students with significant
- plan effective, person-centered transition services for high school students as they pursue PSE
- support students as they manage the practical aspects of a positive PSE experience (see box)
- connect students' PSE experiences directly to employment and their other individual life goals
- discover how exciting legislation and policy changes will affect future PSE options

Throughout the book, vignettes and first-person narratives from students and families underscore the benefits and challenges of PSE, and detailed profiles of real programs illustrate what a wide range of postsecondary options look like.

Readers will also get the helpful tools they need to create effective programs and ease students' transition



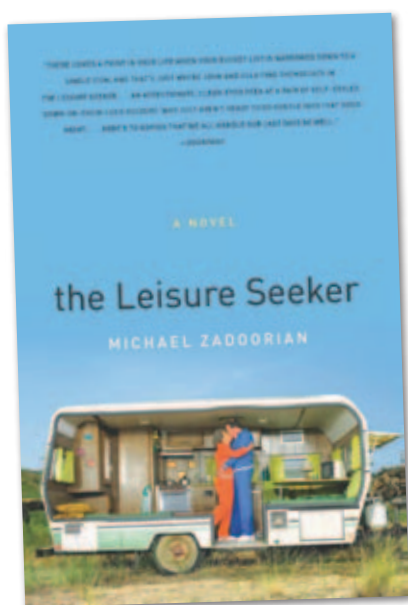


to PSE, including a self-advocacy checklist, a program evaluation tool, sample student schedules, and a college-planning checklist for students and families.

With this thorough guide to today's PSE options and tomorrow's possibilities, professionals will help students with intellectual disabilities take full advantage of their educational opportunities —and set the stage for a successful, fulfilling community life.

## The Leisure Seeker

by Michael Zadoorian



**Synopsis:** John and Ella Robina have shared a wonderful life for more than fifty years. Now in their eighties, Ella suffers from cancer and has chosen to stop treatment. John has Alzheimer's. Yearning for one last adventure, the self-proclaimed "down-on-their-luck geezers"

kidnap themselves from the adult children and doctors who seem to run their lives to steal away from their home in suburban Detroit on a forbidden vacation of rediscovery.

With Ella as his vigilant copilot, John steers their '78 Leisure Seeker RV along the forgotten roads of Route 66 toward Disneyland in search of a past they're having a damned hard time remembering. Yet Ella is determined to prove that, when it comes to life, a person can go back for seconds—sneak a little extra time, grab a small portion more—even when everyone says you can't.

Darkly observant, told with humor, affection, and a touch of irony, *The Leisure Seeker* is an odyssey through the ghost towns, deserted trailer parks, forgotten tourist attractions, giant roadside icons, and crumbling back roads of America. Ultimately it is the story of Ella and John: the people they encounter, the problems they

overcome, the experiences they have lived, the love they share, and their courage to take back the end of their own lives.

## Anything But Typical

by Nora Raleigh Baskin



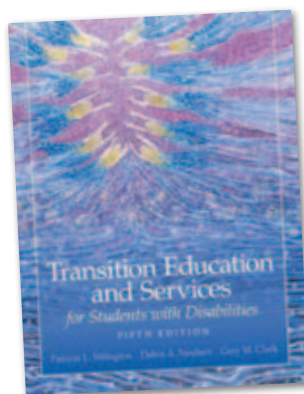
**Synopsis:** Jason Blake is an autistic 12-year-old living in a neuro-typical world. Most days it's just a matter of time before something goes wrong. But Jason finds a glimmer of understanding when he comes across Phoenix Bird, who posts stories to the same online site as he does.

Jason can be himself when he writes and he thinks that Phoenix Bird-

her name is Rebecca—could be his first real friend. But as desperate as Jason is to meet her, he's terrified that if they do meet, Rebecca will only see his autism and not who Jason really is by acclaimed writer Nora Raleigh Baskin, this is the breathtaking depiction of an autistic boy's struggles—and a story for anyone who has ever worried about fitting in.

## Transition Education and Services for Students with Disabilities

by Patricia L. Sitlington, Gary M. Clark, Debra Neubert



**Synopsis:** The Individuals with Disabilities Act of 2004 is making substantial changes in the planning and delivery of transitional services. In addition, more

elementary and middle school children are receiving services. Both situations are reflected in this edition, along with a new focus on getting students ready for their lives as adults as well as preparing them academically. Chapters address legislation, families, and the formative K-8 years, program elements such as assessment, transition to college or employment and independent living, resources, and program implementation techniques. Annotation ©2004 Book News, Inc., Portland, OR

## More than a Job: Securing Satisfying Careers for People with Disabilities

by Paul Wehman (Editor), John Kregel, John Kregel

**Synopsis:** This consumer-driven book provides professionals with step-by-step strategies for helping people with physical and developmental disabilities find meaningful employment. Emphasizing the importance of long-term planning and individualized

control over assessment and training, this practical resource lays out guidelines for pinpointing consumer interests, charting a career path, and identifying employment options.

The editors and chapter authors, many of whom have disabilities themselves, also discuss issues such as transition from school to adult life, transportation, social relationships, and community access. For employment specialists, secondary special education teachers, work-study personnel, advocates, and rehabilitation counselors and therapists, this resource facilitates the day-to-day support that people with disabilities need as they strive to achieve their own personal career goals.



## New Edition of Tuberous Sclerosis Complex Book Now Available

### Tuberous Sclerosis Complex: Genes, Clinical Features and Therapeutics

Edited by David J. Kwiatkowski, Vicky Holets Whittemore, Elizabeth A. Thiele

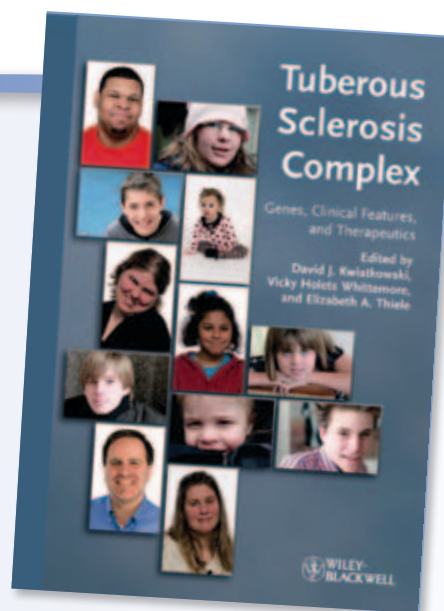
ISBN: 978-3-527-32201-5

Hardcover · 432 pages · Published April 2010

This book offers a comprehensive overview of the molecular basis and clinical features of the genetic disorder tuberous sclerosis complex (TSC). Special focus is placed on novel insights into the signal transduction pathways affected by the disease, genotype-phenotype correlations, recent clinical discoveries and understanding, while existing and potential therapies are also discussed

in depth. The editors are leading experts in research, treatment, and advocacy of the disease.

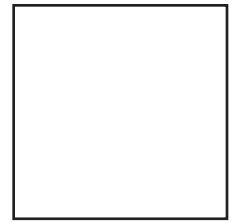
Visit [www.wiley.com](http://www.wiley.com) to find out more about the editors, view the Table of Contents and place an online order. List price is \$119.95, but you can get a special 20 percent discount (\$95.96) by using the promotion code LIFE when ordering.





Tuberous Sclerosis Alliance

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Silver Spring, MD 20910



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